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ABSTRACT

The Center for Independent Living of Greater Bridgeport and its operating agencies conducted a survey of 32 people, the majority of whom were developmentally disabled and residents of institutional or community settings, in both rural and urban areas. The aim of the survey was to determine the perceived needs and levels of independence experienced by these two distinct populations. A questionnaire was developed to gain information on individuals' lifestyles, services used, and levels of satisfaction. Areas addressed were demographics, education, employment and training, income and benefits, housing, recreation and leisure time, transportation, as well as medical treatment, counseling, advocacy, and legal issues. Overall, the findings showed that people living in the community reported greater satisfaction and better use of both generic and categorical services in several areas including transportation, vocational training and options, and living situations. It was concluded that people living in the community reported a greater level of independence and fewer needs than their institutionalized peers. (Author/KC)

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Perceived Needs of Developmentally Disabled Skilled Care Facility and Intermediate Care Facility Residents as Compared to Their Non-institutionalized Peers

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ABSTRACT

The Center for Independent Living of Greater Bridgeport and its cooperating agencies conducted a survey of 32 people, the majority of whom are developmentally disabled and reside in (a)institutional or (b) community settings, in both rural and urban areas.

This report addresses the perceived needs and levels of independence experienced by these two distinct populations. A questionnaire was developed to gain information on individuals' lifestyles, services utilized, and levels of satisfaction. Areas addressed were: demographics, education, employment and training, income and benefits, housing, recreation and leisure time, transportation, and medical treatment, counseling, advocacy and legal issues.

The objective in completing this study was to determine what, if any, differences exist between those in institutionalized and non-institutionalized groups regarding their perceived needs and levels of independence. Overall, the findings showed that people living in the community reported greater satisfaction and better utilization of both generic and categorical services in several areas including transportation, vocational training and options, and living situation. It can be concluded that people living in the community report a greater level of independence and fewer needs than their institutionalized peers.

PERCEIVED NEEDS REPORT

Introduction

In October 1982, the Center for Independent Living of Greater Bridgeport (CILGB), in cooperation with Bridgeport's Office of Handicapped Services (OHS) and the Western Connecticut Association of Handicapped and Retarded, Inc. (WeCAHR), received a Developmental Disabilities Grant of National Significance from the U.S. Department of Health and Human Services (HHS). As part of this project, CILGB established a Computerized Coordinated Service Center (CCSC). CCSC (a) expands services in targeted urban and rural areas, (b)utilizes advanced technology, (c)surveys generic and categorical services available to people with disabilities, and (d)conducts studies and reports on major findings, with implications of interest to those involved with the quality of life of persons with disabilities. In July 1983, CCSC conducted a survey of people with disabilities, their families and/or their advocates, and professionals. This report summarizes the results.

This report addresses the perceived needs and level of independence experienced by developmentally disabled residents of Skilled Care Facilities (SCF's) and Intermediate Care Facilities (ICF's) as compared to their non-institutionalized peers. The survey was conducted in two targeted areas, one urban and one rural. The city of Bridgeport and the surrounding communities comprised the urban area. The city of Danbury and the surrounding towns represented the rural (sub-urban) sector. The principal aim of the study was twofold: (a)to determine consumer satisfaction with services and document any service gaps identified through consumer input and (b)to attempt to identify cost-effective or cost-free program modifications that might improve the quality of life for developmentally disabled persons.

This report will address several important aspects involved in the survey including (a)the methodology utilized, (b)the results of the consumer surveys, (c)the results of the surveys involving SCF and ICF professional staff members, (d)a summary, and (e)conclusions addressing the perceived needs of developmentally disabled persons.

Methodology

Initially, two sample consumer groups involving distinct populations were surveyed. Group A included people who were living in an institutional setting. All of the individuals in Group A were residents of SCF's or ICF's, including nursing homes and group homes. Group B consisted of people who were living in a non-institutionalized, more independent living situation. The individuals in this group were community-based residents including people living at home, in a group living facility, or in a transitional living program. The majority of the individuals surveyed were developmentally disabled and had previously received CILGB services.

The criteria used in identifying potential survey participants included: (a)whether or not the individual was receiving CILGB services at the time of the survey, (b)the ability to comprehend the survey subject matter, and (c)the individual's willingness to participate in the survey. Confidentiality was guaranteed to all participants.

Due to the specific population chosen to be surveyed, it was not appropriate or necessary to conduct a random sample.

Potential participants were chosen from the total number of non-duplicated people -- a total of 96 -- served by the CILGB case management staff during the month of July 1983. Initially, 23 individuals -- residents of SCF and ICF facilities -- from this pool of potential candidates were placed in a subgroup; the remaining individuals constituted a second subgroup. Final candidates for both Group A and Group B were subsequently chosen based on ability to comprehend the survey's subject matter as well as the willingness to participate in the survey. Moreover, candidates for Group B were selected, when appropriate, if they had previously resided in an institutional setting and subsequently moved to a more independent, community-based setting. In addition, a modified questionnaire was distributed to SCF and ICF staff to gather information on their perception of residents' needs and quality of life.

Instrument Development

A questionnaire-type format was selected as the instrument for conducting the consumer satisfaction survey. Participants were offered a limited number of response options, with some opportunity for discussion or elaboration available. (See Appendix A.)

The SCF and ICF staff survey contained both closed and open ended questions. This questionnaire allowed for professional input and discussion regarding the needs of residents and the staff's perception of their ability to utilize community services. (See Appendix B.)

Design of Survey

The survey was developed by focusing on areas and elements that generally affect an individual's quality of life. The questionnaire was designed to gain information on individuals' present lifestyles, services they have utilized, and the level of satisfaction they have experienced with these services. The specific areas addressed were demographics, education, employment and training, income and benefits, housing, transportation, and recreation and leisure time, as well as medical, counseling, advocacy, and legal issues. A section addressing utilization of and satisfaction with CILGB services was also included. The desired outcome of the survey was that the information gathered would convey the actual level of independence perceived and experienced by the participating individuals; significant differences between the two groups were expected.

The initial draft of the survey was formulated by the CILGB Facilities Case Manager. After consulting with the Project Director, the Coordinator of Human Resources, and the CILGB staff, suggestions were incorporated into the format, where appropriate. Subsequently, the final copy was formulated and prepared for distribution.

Data Gathering

Prior to implementing the survey, a training session was held for the CILGB case managers responsible for conducting the interviews. In this session, a final review, including clarification of specific

questions involved in the survey, was made. Interviewing techniques were also discussed. An in-person, one-to-one interview technique was chosen as the method for conducting the survey. It was decided to conduct the survey over a short period of time -- two weeks -- in order to facilitate a prompt and total response rate.

Four staff members from several SCF's known to CILGB were contacted by telephone and asked to participate in the staff survey. The survey was subsequently mailed to each interested staff person -- two from the urban area and two from the rural area.

Response Rates

For Group A, the initial goal was to interview 10 developmentally disabled SCF and ICF residents. Eventually, 11 were interviewed -- five from the rural area and six from the urban area. Of the group, only one person had not previously received any CILGB services.

For Group B, the initial goal was to interview 20 consumers, their families, and/or their advocates. Eventually, 21 people were interviewed; the majority were consumers, seven from the rural area and 14 from the urban area.

The response rate for the staff survey resulted in two completed questionnaires from the urban-based staff members and one response from the rural-based staff members.

Data Analysis

Because of the small total number of consumer satisfaction surveys undertaken and completed, the Facilities Case Manager recorded all responses manually. Totals were checked by other staff members in order to ensure accuracy.

FINDINGS

Demographics

The total sample consisted of 32 participants. Of these, 11 resided in SCF or ICF facilities; 21 were residents of a non-institutionalized, community setting. Table 1 gives a demographic breakdown of the participants.

Table 1

Demographics

AREA	GROUP A		GROUP B	
	No.	%	No.	%
Urban	6	54.5	14	67
Rural	5	45.5	7	33
Total	11	100	21	100

GENDER				
	No.	%	No.	%
Male	4	36	14	67
Female	7	64	7	33
Total	11	100	21	100

MARITAL STATUS				
	No.	%	No.	%
Never Married	8	73	18	85.71
Married	2	18	1	4.76
Separated	0	0	1	4.76
Widowed	1	9	0	0.00
Divorced	0	0	1	4.76
Total	11	100	21	100.00 (99.99)

AVERAGE NUMBER OF YEARS IN AREA		
Urban	9.9 yrs	13.9 yrs
Rural	7.0 yrs	18.6 yrs

No distinct pattern of age distribution was clearly discernible. However, the majority of the participants -- 66% -- were between 21 and 40 years old. It is also noteworthy that none of the members of Group B were over age 50 whereas almost one-third -- 27% -- of the "institutionalized" respondents were over age 50. Table 2 shows the actual age distribution.

Table 2

Age Distribution

Age	GROUP A	GROUP B
Under 21	1	2
21 - 30	3	10
31 - 40	2	6
41 - 50	2	3
51 - 60	1	0
61 - 70	1	0
71 +	1	0
Total	11	21

Disability

Participants were asked to indicate the nature of their primary disability. Table 3 represents the respondents' answers within their respective groups:

Table 3
Disability

DISABILITY	GROUP A		GROUP B	
	No.	%	No.	%
Mental Retardation	3	27	2	9.5
Physical Disability	8	73	8	38.0
Mental Disability	0	0	0	0.0
Visual Impairment	0	0	1	4.8
Hearing Impairment	0	0	0	0.0
Learning Disability	0	0	2	9.5
Multiple Disabilities	0	0	7	33.3
Other (Traumatic Brain Injury)	0	0	1	4.8
Total	11	100	21	100.0

Individuals with a physical disability were asked to indicate their specific disability in order to more accurately describe the population surveyed and to identify those with developmental disabilities. Table 4 illustrates a breakdown by physical disability. (One participant from Group B did not indicate his/her physical disability.)

Table 4

Physical Disabilities

DISABILITY	GROUP A	GROUP B
Cerebral Palsy	4	2
Spinal Cord Injury	1	4
Multiple Sclerosis	2	0
Paraplegia	1	0
Spina Bifida	0	1
Unknown	0	1
Total	8	8

Seven participants from Group B reported multiple disabilities, described as follows: (a)quadraplegia and brain injury, (b)schizophrenia, visual impairment, and amputation, (c)Friedreich's Ataxia and heart disease, (d)cerebral palsy and mental retardation, (e)spinal cord injury and traumatic brain injury, (f)cerebral palsy and visual impairment, and (g)visual disability, Endocrine Adenomatosis Type II, ileostomy, and thyroid cancer.

The majority of the respondents were disabled from birth; 81% indicated that their disability was developmental. Table 5 provides a breakdown of the respondents' ages at the onset of their disability.

Table 5
Age at Onset

AGE	GROUP A	GROUP B
Birth	7	12
Under 22 yrs.	1	6
22 yrs. and Over	3	3
Total	11	21

Education

Almost two-thirds -- 62.5% -- of all participants interviewed were high school graduates or had received their Graduate Equivalency Diploma (G.E.D.), or post high school education. This was true for both groups (Group A - 64%; Group B - 62%). Slightly over one-third (Group A - 36%; Group B - 38% =37.5%) had not completed their high school education. Sixteen percent of the total group had achieved an educational level beyond high school. Interestingly, approximately the same percentage of Group A respondents -- 18% of Group A as opposed to 19% in Group B -- had also received vocational training or rehabilitation in addition to their academic education. One member of Group B had received only vocational training.

Table 6 indicates the levels of education achieved by all respondents.

Table 6

Education

EDUCATIONAL LEVEL	GROUP A	GROUP B
Less than 8th Grade	1	1
8th Grade	0	5
Some High School	3	1
High School Graduate	2	11
Graduate Equivalency Diploma	2	0
Some College	3	1
College Degree	0	0
Graduate Degree	0	1
Vocational Training Only	0	1
Total	11	21
Also Vocational Training	2	3
Also Vocational Rehabilitation	0	1

Respondents were also asked to indicate their level of satisfaction with their education. The results appear in Table 7. The responses indicate a direct relationship between education received and level of educational satisfaction. Of the 20 participants who graduated from high school or college, 80% were either satisfied or very satisfied with their education. Only 42% of those without a high school or college education were satisfied or very satisfied with their education. All of the seven individuals who received either vocational training or rehabilitation (six of whom also received academic education) were satisfied or very satisfied.

Table 7

Satisfaction with Education

EDUCATIONAL LEVEL	VERY SATISFIED	SATISFIED	DISSATISFIED	VERY DISSATISFIED
Less than 8th Grade	0	0	0	2
8th Grade	0	2	3	0
Some High School	0	2	1	1
High School Graduate	2	7	3	1
Graduate Equiv. Diploma	1	1	0	0
Some College	0	4	0	0
College Degree	0	0	0	0
Graduate Degree	1	0	0	0
Vocational Train. Only	1	0	0	0
Total	5	16	7	4
Also Vocational Train.	3	2	0	0
Also Vocational Rehab.	0	1	0	0

Participants were also asked what community agency, organization, or individual had been helpful to them in educational endeavors. A variety of responses were received. Forty-six percent cited the Division of Vocational Rehabilitation (DVR), nine percent cited CILGB, and nine percent cited School Personnel.

Employment and Training

Table 8 denotes the employment status of the individuals who participated in the survey. The total number of respondents will surpass 100% since multiple answers were given by some respondents. Explanations of multiple responses follow Table 8.

Table 8

Employment

EMPLOYMENT STATUS	GROUP A	GROUP B
Full-time Employment	0	2
Part-time Employment	2	1
Sheltered Employment	3	6
Volunteer Work	0	2
Student/In Training	1*	2**
Homemaker	0	0
Unemployed, Underemployed, or Seeking Employment	1****	5***
Unemployed, Not Seeking Employment	2	3
Considered Unemployable	4	2
Other (Unemployed - Waiting to Return to Former Job)	0	1

Explanation:

* This person is also employed in a sheltered workshop.

** One individual in training is also employed in a sheltered workshop.

*** One person is also employed part-time, and another person does volunteer work, while seeking employment. Only the latter was considered unemployed in this survey.

**** This person is also included in the Considered Unemployable category.

Employment status for both groups was similar, indicating that institutional versus non-institutional living situation did not seem to effect employment status. In both groups, a high percentage -- 55% in Group A and 57% in Group B -- of the respondents were unemployed. Unemployed was defined as (a)seeking employment, (b)not seeking employment, (c)considered unemployable, (d)performing some type of volunteer work, or (e)other.

Employment in a sheltered workshop was the second highest category for respondents; 27% of Group A and 29% of Group B fell into this category.

Eighteen percent of the individuals in Group A and 14% in Group were competitively employed, either part-time or full-time.

Respondents who were employed were asked to record their level of satisfaction with their employment situation. In Group A, four individuals were satisfied and one individual was very satisfied. Six individuals from Group A did not respond or felt the question non-applicable to their situation. In Group B, six people were satisfied, one was very satisfied, and three were dissatisfied with their employment situation. Eleven felt that this question was not applicable to their situation.

Training

Generally, Group B (non-institutionalized) respondents were more involved in and satisfied with training and vocational counseling and career opportunities. Four people in Group A (36%) participated in training programs and all were satisfied. Eleven people in Group B (55%) were involved in some type of training program; five were satisfied, four were very satisfied, and two expressed dissatisfaction. One person in Group B did not respond to this question.

Only 50% of people residing in SCF's or ICF's responded affirmatively when asked if they had met with either a career, job, or vocational rehabilitation counselor. Ninety percent of the participants in Group B had such an opportunity.

Regarding satisfaction with career options, institutionalized participants appeared to have less vocational career options available to them. Only three, or 30% were satisfied. One, or 10%, responded as dissatisfied. Three, or 30%, were very dissatisfied with their options. Three or 30% stated that this question was not applicable to them. One individaul did not respond to this question. In Group B, nine, or 45% of the individuals, were either satisfied or very satisfied with the options available; another seven, or 35%, were either dissatisfied or very dissatisfied, and four, or 20%, responded that the question did not pertain to them. Table 9 summarizes training and career counseling and options data.

Table 9

Training, Career Counseling and Options

INDIVIDUALS WITH TRAINING	GROUP A (N=11)		GROUP B (N=20)	
	No.	%	No.	%
Participant	4	36	11	55
Non-participant	7	64	9	45
Total	11	100	20	100

Table 9 (continued)

SATISFACTION WITH TRAINING*	No.	%	No.	%
Very satisfied with Training	0	0.0	4	20
Satisfied with Training	4	36.3	5	25
Dissatisfied with Training	0	0.0	0	00
Very Dissatisfied with Training	0	0.0	2	10
Not Applicable	4	36.3	9	45
No Response	3	27.3	0	00
Totals	11	100	20	100

* * * *

RESPONDENTS WHO EXPRESSED SATISFACTION				
Satisfied or Very Satisfied	4	10	9	82
Dissatisfied or Very Dissatisfied	0	00	2	18
Totals	4	100	11	100

* * * *

CAREER COUNSELING**				
Participant in Counseling	5	50	19	90
Non-participant	5	5	2	10
Totals	10	100	21	100

* * * *

SATISFACTION WITH CAREER OPTIONS**				
Very Satisfied	0	0	1	5
Satisfied	3	30	8	40
Dissatisfied	1	10	5	25
Very Dissatisfied	3	30	2	10
Not Applicable	3	30	4	20
Totals	10	100	20	100

* Based on 20 respondents from Group B.
** Group A based on 10 respondents, Group B based on 21 respondents.

Suggestions on how to help an unemployed person obtain a job were also generated. A variety of responses included general answers such as provision of college, schooling and/or training, typing or computer training, and a van (appropriately adapted) for transportation. Several people expressed uncertainty as to what would help them obtain a job.

When information on employment is needed, the majority of the respondents went to the Division of Vocational Rehabilitation (DVR) --

(36%) in Group A and 14 (67%) in Group B. CILGB was utilized as another source of information -- 2 (18%) in Group A and 6 (29%) individuals in Group B. Other answers included the Veterans Administration, State Job Service, and a variety of local agencies serving disabled persons. The latter include rehabilitation services, sheltered workshops etc.

Income and Benefits

The majority of the participants receive financial benefits from either a federal or state funding source. All of the people residing in SCF's and ICF's received Title XIX medical benefits; only 43% of the community based people received Medicaid benefits. A high percentage of both Groups received some Social Security benefits (Group A - 81%; Group B - 76%). In the questionnaire, respondents were asked to check all income sources received. A summary of responses shows many people received income from more than one source.

Forty-five percent of institutionalized persons received wages from employment; virtually all of this employment was either within a nursing home or some type of sheltered setting. Thirty-three percent of non-institutionalized persons received income from their employment.

Nine percent of Group A particpants relied upon family support. Twenty-nine percent of the people living in a more independent living situation received some family support.

One community-based respondent received benefits through the Essential Services program of the Connecticut Department of Human Resources (DHR). There were no individuals receiving services under DHR's Personal Care Assistance program. Likewise, no one received benefits from Worker's Compensation.

Table 10 shows the sources of participants' income or benefits. Multiple responses were recorded.

Table 10

SOURCE OF INCOME	GROUP A		GROUP B	
	No.	%	No.	%
Wages from Employment	5	4	7*	33
Parental/Family Support	1	9	6	29
Employee Pension	1	9	1	5
Workers Compensation	0	0	0	0
SSDI	3	27	7	33
SSI	6	54	9	43
Veteran's Benefits	0	0	1	5
State Supplement	2	18	5	24
City/Town Welfare Assist.	0	0	1	5
State Welfare	0	0	1	5
Essential Services (DHR)	0	0	1	5
PCA Program (DHR)	0	0	0	0
Title XIX	11	100	9	43
Application Pending	1	9	0	0

* Only seven people responded although nine reported being employed - see Table 8.

Most people in both groups expressed the ability to meet basic living requirements with the current income and benefits being received. In this aspect, 72% in Group A and 66% in Group B responded positively. An additional 9% in Group A were able to meet their needs sometimes, while 18% weren't able to meet their basic expenses at all. In Group B, 23% met their needs sometimes, while only 9% felt they could not provide for basic expenses with their present income.

One of Group B respondent's only source of income was wages received from full-time employment. This person indicated an inability to meet his/her desired level of independence since the salary he/she earned was insufficient for funding a Personal Care Attendant and a specially equipped van that he/she needed.

People receiving benefits from state or federal agencies were asked questions relating to the application process. A very high percentage -- 90% of the respondents in Group A and 93% in Group B -- expressed the need for assistance in completing the application forms. Fifty-three percent of the community based participants said that they received help from an agency staff member, while 70% of institutionalized individuals said they did not receive help from a staff member.

The ability to meet eligibility requirements for benefit programs was not a problem for the institutionalized participants. Ninety percent of the respondents reported that they needed no assistance. One individual from Group A did not respond to this question. Sixty-seven percent of the community respondents indicated the need for help with eligibility requirements. Six individuals from Group B did not respond to this question.

A wide variety of sources were cited by both groups as being valuable in obtaining help in the area of income and benefits. The federal or state agency and CILGB were indicated as the most helpful. Nursing homes, hospitals, family members, and local rehabilitation agencies were also cited.

Housing

Individuals residing in Skilled Care facilities made up the greatest proportion -- 73% -- of respondents in Group A. People living in ICF group homes comprised the remaining 27%.

Of the individuals sampled in Group B, nine, or 43%, lived with family members and five, or 24%, lived alone. The remaining respondents lived either (a)with spouse or children, (b)with children and roommates, (c)in a long-term group living facility, or (d)in a transitional living program. Three of the 21 community-based respondents lived in Section 8 subsidized housing units.

Sixty-four percent of the people in Group A were very dissatisfied with their current living situation; an additional nine percent were dissatisfied. Consequently, a total of 73% were unhappy to some degree. In contrast, 66% of the people in Group B were either very satisfied or satisfied with their current living situation. Yet, when asked if they would prefer another living situation the majority in both groups responded affirmatively (Group A - 82%; Group B - 66%). Moreover, the overwhelming choice of an alternate living arrangement in both groups was to live independently in a private apartment (with a Personal Care Attendent, if necessary). Eight individuals in Group A (73%) and twelve in Group B (57%) expressed a desire to have their own apartments; of these, three in each group indicated the need for a Personal Care

Attendant (PCA) in such a situation One person in Group A wanted a more private living situation and two did not want to change their current living situation. The responses from the remaining individuals in Group B were somewhat similar: one wished to have a nicer apartment and one longed for a place where he/she could be totally independent. Seven individuals desired no change. These wishes are reported in Table 11.

Table 11

Alternate Living Situation

DESIRED LIVING SITUATION	GROUP A	GROUP B
Own Apartment	5	9
Apartment with Personal Care Attendant	3	3
More Private Situation	1	0
"Nicer" Apartment	0	1
"Total Independence"	0	1
No Change	2	7
Total	11	21

Participants felt numerous factors were preventing them from obtaining their desired living situation. The major hinderances for individuals living in SCF's and ICF's were a need for PCA services, a need for further Independent Living Skills (ILS) instruction, and the lack of available housing and transportation. Persons in the community-based group also mentioned somewhat similar obstacles. The majority listed a lack of money as the most significant; a lack of available housing, a need further ILS instruction, and a lack of transportation were also cited as major factors.

Table 12 illustrates the variety of factors that respondents perceived as preventing them from becoming more independent. Although some factors were chosen more often than others, it is apparent that many issues are involved. Multiple responses are recorded. Group A data is based upon a total of eight respondents who felt the question applied to them. Group B data is based upon a total of 17 respondents; four individuals felt the question did not apply to them and one individual did not respond.

Table 12

Factors Preventing Respondents
From Obtaining a Desired Living Situation
(Group A = 8, Group B = 17)

REASON	GROUP A		GROUP B	
	No.	%	No.	%
Lack of Money	4	50	10	59
Lack of Affordable Housing	4	50	6	35
Lack of Available Housing	6	75	9	53
Lack of Accessible Housing	5	63	6	35
Lack of Transportation	6	75	7	41
Need for PCA Services	6	75	5	29
Need for ILS Instruction	6	75	8	47
Other	1	13	2	12

Respondents in both groups cited several sources as being helpful in the area of housing. CILGB was mentioned by both groups most frequently. The State Office of Protection and Advocacy, the State Regional Center in the rural area, and hospitals in both areas were also chosen by respondents.

Recreation and Leisure

Respondents in both groups spent their leisure time by participating in a diverse number of activities. Frequently, however, activities undertaken were passive in nature. Typical passive activities might include watching television or listening to the radio, reading, or watching spectator sports. All of the respondents in Group A and 95% in Group B utilized some leisure time watching television or listening to the radio.

The major differences in leisure time activities were evident in spectator sports, hobbies or crafts, and reading. Table 13 delineates the types of activities in which respondents engaged. Multiple responses are recorded.

Table 13

Recreation and Leisure Time Activities

TYPE OF ACTIVITY	GROUP A		GROUP B	
	No.	%	No.	%
Go Out for Evening	8	73	15	71
Participate in Sports	5	45	7	33
Spectator at Sporting Events*	1	9	7	33
Hobbies or Crafts	8	73	8	38
Visiting	8	73	18	86
Go On Trips	6	55	10	48
Shopping	7	64	15	71
TV, Radio*	11	100	20	95
Reading*	9	82	10	48
None	0	0	0	0
Other	1	9	3	14

* Considered a passive activity.

A majority of both groups expressed varying degrees of dissatisfaction with the availability of recreation and/or leisure time activities. The dissatisfaction was particularly evident in persons residing in an institutional setting; 82% of these respondents were either dissatisfied or very dissatisfied. While the level of dissatisfaction in Group B respondents (only 19 of 21 responded to this question) was still rather high -- 63% -- a difference between the two groups does exist.

An overwhelming majority -- 90% from Group A and 89% from Group B expressed a desire to participate more often in recreational activities. When asked how they learned of available programs, the institutionalized group reported relying on the media (55%) and friends (45%) for information. Community-based participants asked friends (57%) or went to an agency or organization (52%) to learn of available recreational activities. Most respondents felt a variety of factors prevented them from participation in activities. Lack of transportation, in particular, was cited as the biggest problem. Table 14 cites respondents' reasons for lack of participation in leisure activities. Data is recorded for both groups based upon the total number of respondents who felt the question pertained to them; five from Group A and fifteen from Group B. Multiple responses are recorded.

Table 14

Reasons Cited for Lack of Participation in Recreational Activities
(Totals of Group A = 5; Group B = 15)

REASON	GROUP A		GROUP B	
	No.	%	No.	%
Lack of Transportation	5	100	8	53
Lack of Money	3	60	6	40
Lack of Interest	2	40	5	33
Lack of Companionship	5	100	5	33
Lack of Knowledge	2	40	4	27
Lack of Accessibility	4	80	4	27
Other	1	20	2	13

Transportation

There was a marked difference in the degree of satisfaction with transportation services. Of the 11 members of Group A, 64 were very dissatisfied with available transportation. In this group, 70% depended upon family members or friends for rides; 60% used transportation for "the handicapped," and 50% utilized an agency or facility van. Most of these respondents used more than one means of transportation.

The lack of transportation alternatives was the most frequently cited complaint of the seven Group A members who felt this question applicable to their situation. One hundred percent cited this as a prime reason; 71% listed accessibility; and 57% felt that the lack of sufficient routes and/or locations for public transportation was a major obstacle.

The responses from persons in Group B were quite different from those of their institutionalized counterparts. A majority of the community-based residents -- 72% of the 18 who responded -- were either satisfied or very satisfied when asked to rate transportation services. Only 28% percent were not satisfied. As with the respondents from Group A, most of the individuals in Group B -- 67% -- relied upon family members and friends as their major transportation provider. Thirty-three percent reported using transportation for "the handicapped" and thirty-three percent reported using public transport.

It was apparent that the community-based group had fewer overall problems with transportation than their insitutionalized counterparts. Twelve people (57%) thought that the question relating to dissatisfaction with transportation services did not apply to them. Two individuals (9.5%) did not respond to the question at all. Of the remaining individuals, 86% felt that the lack of availability was indeed a problem; and 57% cited the lack of routes.

People in Group A tended to rely on established agencies as opposed to generic community resources such as the newspapers for information on transportation.

Group B respondents reported that they obtained information on transportation through CILGB (10 people), other agencies dealing with

people with disabilities (6), other agencies (not specified) (5), family (2), and other generic community resources (3). Tables 15 and 16 summarize modes of, problems, and satisfaction with transportation. Multiple responses are recorded.

Table 15

Modes of Transportation

TYPE OF TRANSPORTATION	GROUP A* (n=10)		GROUP B (n=21)	
	No.	%	No.	%
Drive Own Vehicle	0	0	3	14
Family/Friends Drive	7	70	14	67
Agency/Facility van	5	50	5	24
Public Transit	2	20	7	33
Handicapped Trans.	6	55	7	33
Specially Equipped Veh.	0	0	1	5
Other	1	10	0	0
No Response	1	10	0	0

* Only 10 of the 11 people in Group A responded to this question. Percentages are based on total of 10.

Table 16

Transportation*

SATISFACTION WITH TRANSPORTATION*	Group A		Group B	
	No.	%	No.	%
Very Satisfied	1	9	4	22
Satisfied	3	27	9	50
Dissatisfied	0	0	0	0
Very Dissatisfied	7	64	5	28
Totals	11	100	18	100

PROBLEMS WITH TRANSPORTATION	GROUP A (n=7)		GROUP B** (n=7)	
	No.	%	No.	%
Lack of Availability	7	100	6	86
Cost of Transportation	2	29	2	29
Accessibility	5	71	3	43
Not Enough Routes	4	57	4	57
Other	0	0	3	43
No response	0	0	3	14

** One person in Group B responded that they were satisfied with the transportation services available to them; however, they cited a lack in available transportation. Another respondent in Group B did not express his/her degree of satisfaction/dissatisfaction but did express a need for more information on what transportation services were available to him/her. Both of these individuals' responses were included in the section on Problems With Transportation. Three individuals from Group B did not respond to either the question on satisfaction/dissatisfaction or the question on problems with transportation.

Medical

Medical care or treatment is received by a very high percentage of individuals residing in SCF's and ICF's. Eighty-two percent visit a doctor regularly and 90% take medication regularly. In sharp contrast to this, slightly over 50% of Group B visit a doctor on a regular basis and only 57% take medication medication regularly. Individuals in the latter group do, however, receive more physical, occupational and/or speech therapy than their counterparts -- 8 persons, or 38% from Group B, as opposed to only one person, or less than 10%, from Group A. Seventyfive percent of individuals in both groups reported some degree of satisfaction with medical services.

Tables 17 and 18 summarize the sources of medical services received and the places where information on medical services was obtained. One individual from Group A did not respond to the question represented in Table 17. Multiple responses are recorded.

Table 17

Source of Medical Services

SERVICE SOURCE	GROUP A (n=10)		GROUP B (n=21)	
	No.	%	No.	%
Private Doctor	2	20	10	48
Hospital	2	20	6	33
Home Health Care	0	0	3	14
Clinic	1	10	7	33
Rehab. Center	2	20	1	5
Nursing Home	5	50	0	0
Not Applicable	0	0	3	14
Other	0	0	0	0

Table 18

Information on Medical Services

INFORMATION SOURCE	GROUP A (n=11)		GROUP B (n=21)	
	No.	%	No.	%
Agency/Organization	3	27.2	11	52.4
Individual	1	9.1	2	9.5
Doctor	5	45.4	11	52.4
Other	2	18.2	4	19.0

Counseling

Individuals from both groups received counseling on a variety of topics and from a variety of sources.

Counseling on Independent Living was received by the largest percentage of the members of both Group A and Group B; 64% of the former and 81% of the latter benefitted from this service. Counseling on sexuality was in sharp contrast to this. Only 22% of the combined groups received this type of service. A slight difference in the groups' perceived level of satisfaction with counseling services was also evident. Seven out of the nine persons (78%) in Group A who responded to the question addressing this issue were either satisfied or very satisfied. Seventeen out of eighteen respondents (94%) in Group B had positive reactions.

Agencies were cited as the greatest source of counseling information for both groups. The highest percentage of both groups utilized the Independent Living Center and public counselors or social workers. Families and doctors were also used for information regarding counseling services by both groups. The remainder of respondents from both groups utilized other resources such as schools, DVR and hospitals.

Tables 19 and 20 depict the type of counseling sought and the source of counseling services utilized. Multiple responses are recorded.

Table 19

Type of Counseling

TYPE	GROUP A (n=11)		GROUP B (n=21)	
	No.	%	No.	%
Accepting/coping with disability	6	55	6	29
Personal issues	6	55	5	24
Sexuality	4	36	3	14
Indep. Living Counseling	7	64	17	81
Benefits	2	18	8	38
None	3	27	2	10
Other	0	0	1	5
No Response	0	0	0	0

Table 20

Source of Counseling

SOURCE	GROUP A (n=11)		GROUP B (n=21)	
	No.	%	No.	%
Public counselor/Social Worker	5	45	13	62
Private Counseling Agency	4	36	4	19
Independent Living Ctr.	7	64	16	76
Medical Professional	1	9	5	24
Clergy Member	2	18	4	19
Peer/Support Group	1	9	3	14
Family/Friends	3	27	7	33
Not applicable	3	27	2	10
Other	1	9	0	0
No Response	0	0	0	0

Advocacy and Legal Issues

A high level of awareness of legal rights was apparent in all 32 respondents. Sixty-four percent of Group A and 71% of Group B stated that they were knowledgeable about their rights. However, a significant difference in ways of obtaining knowledge about legal rights was noted. A large percent (45%, or 71% of those responding to this question) of the people residing in SCF's and ICF's reported that they rely on their own knowledge; community-based people were more apt to seek professional advice through a specialized agency (52%, or 73% of those responding to this question). Table 21 indicates where people gain information concerning their legal rights. Multiple responses are recorded.

Table 21

Source of Information

SOURCE	GROUP A (n=11)		GROUP B (n=21)	
	No.	%	No.	%
Own Knowledge	5	45	8	38
Research	3	27	3	14
Family	1	9	4	19
Friend	2	18	4	19
Agency	3	27	11	52
Other	1	9	1	5
No Response	4	36	6	29

Some members of both groups -- 36% of Group A and 29% of Group B -- expressed a lack of awareness regarding legal rights. Two Group A respondents stated they were unaware because they didn't know where to get information, while two cited "other" with no explanation. Group B members cited multiple reasons for their ignorance about legal matters; included were: (a)the complexity of legal rights, (b)not necessary to know about rights, and (c)the lack of knowledge about where to get information. Two responded "other" with no explanation.

A majority of participants from both groups had some type of involvement with an agency that advocates for the civil rights of persons with disabilities. No significant difference between the groups was evident; 71% from Group B, and 64% from Group A responded affirmatively.

Regarding satisfaction with advocacy services, ten members of Group A responded. Two of the ten felt the question nonapplicable to their situation, seven (70%) were satisfied or very satisfied, and one individual was unaware of what advocacy services were provided. A total of twenty community residents responded; four felt the question non-applicable to them. Of the remaining sixteen, fifteen (94%) were satisfied or very satisfied.

The sample groups chose a large array of resources to utilize for help in advocating for their rights. Group A respondents chose either (a)an advocacy agency, (b)an Independent Living Center, or (c)a rehabilitation or sheltered workshop agency. The community-based residents in Group B were more diverse in citing the resources utilized. In addition to choosing the same type of resources previously presented, sources such as DVR, lawyers, the governor, the Human Rights Commission, etc., were also cited.

CILGB Services

All participants surveyed, except for one institutionalized individual, received or participated in CILGB services. In accordance with this, respondents were asked to express their level of satisfaction with all CILGB services received. Table 22 provides a

summary of the responses. One individaul in Group A did not respond to this question. In addition, one individual in Group B who had previously received CILGB services did not respond to this question.

Table 22

Satisfaction with CILGB Services

SERVICE	VERY SAT.		SATIS.		DISSAT.		VERY DIS.	
	Group A	Group B	Group A	Group B	Group A	Group B	Group A	Group B
IL Counseling	4	6	4	9	0	1	0	0
IL Skills Instruction	1	4	2	8	0	0	0	0
Occupational Therapy	0	1	1	2	0	1	0	0
Activities of Daily Living Services	0	0	0	2	0	0	0	0
Housing assistance	2	0	2	5	1	0	0	0
Trans. Living Program	0	0	0	4	0	0	0	0
Personal Advocacy	4	3	4	7	0	0	0	0
Benefits Counseling	1	3	0	5	1	0	0	0
Follow-up Services	0	1	0	1	0	0	0	0
Special Interest Class	1	2	1	2	0	0	0	0
Peer Counseling	0	1	0	1	0	1	0	0
Consumer Action Group	0	0	0	0	0	0	0	0
Volunteer Program	0	0	0	2	0	0	0	0
Cultural/Recreation	0	1	0	2	1	1	1	0
Support Group	0	0	0	2	0	1	0	0
Outreach	6	3	2	3	0	0	0	0
Information & Referral	4	3	0	6	0	0	0	0
PCA referral	2	0	1	0	0	0	0	0

* IL means Independent Living.

Conclusion

The purpose of this report was to address the perceived needs and levels of independence of developmentally disabled SCF and ICF residents as compared to their non-institutionalized peers, in both rural and urban areas. It was anticipated that there would be significant differences between the 2 groups. The total population surveyed was relatively small in size (32 participants). Consequently, the results are not meant to be conclusive of all people with disabilities.

The findings of the survey indicated that the community-based group was significantly more independent and had fewer needs in several areas than the institutionalized group. Transportation for those in the community was more available and satisfactory. On the other hand, people residing in institutions were very dissatisfied with transportation, particularly due to the lack of availability. Transportation is a major service that would promote independence in many areas including employment and recreation.

People living in the community felt a greater degree of satisfaction with their living situation than did people currently residing in institutions.

The other major obvious difference between the two groups was in the area of vocational opportunities. People residing in the community participated more often in some type of training program. They also had more of an opportunity to utilize career or vocational counseling and felt they had more career or vocational options than did their institutionalized counterparts.

* * * *

Community-based services are essential ingredients to achieving independent living, that is, life in the least restrictive environment. Persons with disabilities must be guaranteed further access to the resources necessary to live independently in the community. Services such as transportation, training programs, employment opportunities, housing, recreation, personal care assistance, and independent living programs are just a few of the important areas. It is crucial that people with disabilities, their families and other concerned parties make an intense effort to promote independent living.

This survey has shown that disabled individuals living in the community experience a more independent lifestyle and have less obvious needs than their institutionalized peers. Community living with adequate support systems appears to be a more productive and viable way of life for people with disabilities.

STAFF SURVEY

The purpose of the staff survey was to receive SCF/ICF staff input regarding their preceptions of the needs of developmentally disabled residents who have the potential of utilizing community services. Voluntary staff participants were asked their opinions of (a)services being utilized by their patients (both in the community and in the facility), (b)their patients needs, and (c)what may prevent patients from meeting their needs. Three individuals responded to the staff survey. A questionnaire was developed which included categories similar to the consumer satisfaction questionnaire. Following are the findings of the SCF staff survey.

The staff surveyed consisted of people in supervisory and/or administrative positions (e.g. Directors of Social Services, Coordinators). The percentage of time spent in direct patient contact ranged from 25% to 50%.

The primary developmental disability of patients was indicated by the majority as multiple, including cerebral palsy, multiple sclerosis, and mental retardation. The majority of the developmentally disabled individuals in the SCF had attained a high school education.

In the area of income and benefits staff stated they did help patients apply for benefit programs, but did not spend a great deal of time performing this function. Two staff indicated they had assisted patients in appealing a decision regarding their benefits. Responses regarding income for luxury items, entertainment, etc. varied. One staff person felt that patients' income allowed them "extras"; another felt there was little allowance for outside entertainment (though there were some entertainment and recreational activities available within the facility; and the third stated that patients had very little money ($28/month) for such expenses.

Two staff members felt that the developmentally disabled people in their facilities could live in more independent living situations if they were available. They felt a multitude of services would help those residents achieve a greater degree of independence. These necessary services included funding, available housing, independent living skills and activities of daily living instruction, personal care attendants, transportation, job training, employment, and transitional living programs.

Participants were then asked a series of questions on (a)utilization of services, (b)patients' need for services, and (c)apparent obstacles to utilization of necessary services. All three respondents stated that transportation services were utilized. Staff felt an escort service to medical appointments was a need as were "all forms of transportation services at all times." Exorbitant expense, lack of availability, lack of funds, and lack of aides to accompany patients were cited as reasons for not being able to use transportation services.

In the area of counseling, staff identified sexuality counseling and coping with disability (for both patients and families) as pertinent counseling issues. Staff felt counseling services were not utilized because patients were unwilling to accept counseling and because counseling resources were limited.

More client advocacy was seen as a prevailing need, along with free legal services and representation. Staff felt patients were unaware of their rights and available resources, and lacked information needed to negotiate "the system" and become more aware of community resources and entitlements. Staff generally perceived community resources as "scattered" and thought families and patients needed some continuity to draw them together. Transportation was cited as a reason patients were unable to use advocacy/legal rights services.

Staff thought patients felt the need for a variety of educational and training programs including adult education, DVR/ rehabilitation programs, college courses, driver training, and all types of vocational training, specifically including simple job training. Factors thought to hinder the availability of education and training were (a)inaccessibility to physically disabled people, (b)too costly, (c)lack of transportation options, funding and (d) inability to meet eligibility criteria.

Community medical services were not utilized by any of the patients, according to the staff. They did not indicate that they felt that patients wanted this type of service.

Staff identified a wide variety of recreational and leisure time activities which they felt patients wanted. The list included wheelchair sports activities; more live entertainment; day center programming; hobbies such as hand and wood crafts, painting, etc.; and field trips out of the facility. Staff reported that they sensed patients were unable to use leisure time services because (a)they are not available, (b)lack of funds, (c)lack of transportation, and (d)lack of aides to accompany people on recreational activities. They also felt a lack of interest, loss of interest after initial enthusiasm, and resistance to being grouped with other disabled people discouraged participation.

The small sample does not allow for any major conclusions to be drawn. The report does, however, present some interesting perceptions of how staff members view developmentally disabled patients.